Can routine information systems be used to monitor serious disability?

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Abstract
***Objective*—To determine whether reliable birth cohort prevalence rates of disabling conditions in early childhood can be obtained from child health information systems.**
***Design*—Comparison of two sources of information on motor and sensory disabilities: from child health information systems held by health authorities, and a population register that uses multiple sources of ascertainment.**
***Setting*—The counties of Oxfordshire, Buckinghamshire, and Northamptonshire.**
***Participants*—Children born to residents of the three counties between 1984 and 1989.**
***Results*—Eight hundred and twenty children (6.0/1000 live births) were identified from the child health system as having one or more of the conditions, and 580 (4.2/1000 live births) were identified from the population register; however, only 284 children were identified by both sources.**
***Conclusions*—It is currently impossible to monitor trends in the prevalence rate of disabling disorders in childhood using the child health information systems. Agreement about ways of collecting, recording, and collating information on disability would be a useful step towards realising the full potential of these systems.**
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Information on the frequency, distribution, and characteristics of motor and sensory impairment and disability in early childhood is of value to policy makers, commissioners of health services, providers, and parents. This information is not collected routinely in England and Wales, however, making simple questions about trends and variations in the prevalence of such disorders difficult to answer.[1 2] Some information is available from one off surveys, cohort studies, and population registers, but there is no system that can provide information on trends over time in the prevalence of disability and impairment in the childhood population in England and Wales, let alone allow analyses by birth weight group or by geographical area.

Yet, there are child health information systems, usually run by community trusts for health authorities, which hold data, often computerised, on every child living within the health authority boundaries. Although these systems vary from one district to another,[3] most include information transferred from the birth notification, the immunisation schedule, and some record of the child's health and development.[4] Many districts using the "national child health computing system" include information on the results of screening tests and developmental assessments in the early years on a preschool module. Children with identified health or educational problems usually have further information entered on a "special needs" module. Other child health systems are similar but the information on health and development varies in format, quantity, and quality from one system to another.

The primary purpose of these child health systems is to provide an operational framework for providing appropriate health and educational services to individual children within the area. Attempts to compile population data on the prevalence and characteristics of chronic conditions and disabilities from child health information systems have been less successful and separate systems for collecting information on early childhood impairment and disability have been set up in a number of areas.[5–7]

One such system is a population register of children with cerebral palsy, sensorineural deafness, or severe vision loss in the four counties of Oxfordshire, Northamptonshire, Buckinghamshire, and Berkshire.[8] The register is compiled using multiple sources of ascertainment including health visitors, paediatricians, audiologists, ophthalmologists and orthoptists, child development centres, and community child health registers. Establishing the register was approved by the eight ethics committees in the eight health districts that were included in the Oxford health region in 1984. The definitions used on the register are as follows:

- Cerebral palsy is a permanent impairment of voluntary movement or posture presumed to be a result of permanent damage to the immature brain.
- Sensorineural deafness is a loss of 50 dB or more averaged across the range 0.5–4 kHz in the better ear and, in the absence of an audiogram, all children with a hearing aid fitted for sensorineural loss are included.
- Severe vision loss is a visual acuity in the better eye of 6/18 or less and, if visual acuity cannot be measured, an assessment of the degree of visual impairment is made on the behavioural responses of the child.

After the initial reporting to the register, the status of each child is checked at the age of 3 and 5 years to ensure that the children still

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meet the criteria for a "case". Minimal data on the children are recorded: some demographic, a brief standardised description of the underlying diagnosis, the nature of the impairment, and the level of disability. The register includes data on children with these conditions who were born to mothers resident at the time of birth, the "geographically defined cases", some of whom have moved out of the area. In addition, children with these conditions who have moved into the area are also recorded and are included in the "currently resident cases". When the register was started in 1984, it was thought likely that in due course it would be superseded by the child health systems. At that time these were still at an early stage of development.

This register has now been in existence for 13 years and has been used to monitor birth weight specific prevalence rates of cerebral palsy, sensorineural deafness, and severe vision impairment within a geographically defined area. It has also been a successful framework for aetiological and health services research.[9] During this time, there have been many changes in the organisation of NHS information services at both local and national levels. It seemed timely, therefore, to ascertain whether reliable birth cohort prevalence rates of these conditions could now be derived from existing district based child health systems. Our paper reports attempts to do this.

Methods

There are eight child health information systems in the four counties covered by the register. These were established in the districts that existed from 1981 until the early 1990s. Six of the eight—those in Oxfordshire, Northamptonshire, and Buckinghamshire—use codes from the ninth revision of the *International classification of diseases* (ICD-9) to classify diagnoses and conditions.[10] Two districts in Berkshire did not use ICD codes at the time of the study and so could not be included. The staff responsible for the six systems using ICD-9 were asked to compile a list of the children born between 1984 and 1989 whose condition had been coded with one or more of 87 codes from ICD-9, drawing on information from any of the available modules, including the special needs module. The codes had been selected as those most likely to identify children with cerebral palsy, severe vision loss, or sensorineural deafness.

Concurrently, a list of children with these conditions, born between 1984 and 1989 to mothers resident in the area, was compiled from the population register.

We then compared the two lists. First, using name and date of birth, we identified the children from the list produced from the child health information system who were also identified as cases on the register. The current status of all children on the list generated by the child health information systems who were not included on the register was ascertained by searching hospital and community records or, where necessary, directly from a health professional involved in the care of the children. It was then possible to allocate these children to one of three groups, namely: (1) those children who were not born to a resident of the area; (2) those who were born to a resident of the area, who fulfilled the criteria for inclusion on the register, and were previously unknown to it; and (3) those who were born to a resident of the area but did not fulfil the criteria for inclusion on the register. By this process we could also identify any mismatches that had resulted from name change or confusion between multiples or siblings. Finally, children on the list compiled from the register, who were still alive and resident in the area, but were not included on the list generated by the child health system were identified.

Results

The list compiled from the child health information systems using the 87 ICD codes comprised 820 children. Of these, 126 were born to mothers who lived outside the area at the time of delivery. Of the remaining 694, 284 were found to be on the register and an additional nine children who satisfied the register criteria but were not previously known to it were identified (table 1). This left 401 children on the list who did not meet the criteria for inclusion on the population register.

The register included 580 children born between 1984 and 1989 who had one or more of the three conditions. Of these, 446 were alive and still resident in the area and therefore likely to be identifiable on the child health information system. Of these 446 children, 284 (63.7%) were identifiable as having a motor or sensory disability from the child health information systems and 162 (36.3%) were not (table 2). Based on the population register, the prevalence rate of the conditions was 4.2/1000 live births, whereas based on the child health

Table 1 Children born 1984–89 identified from child health systems as having cerebral palsy, severe vision loss, or sensorineural deafness

District of residence at birth	*Total (n)*	*Born to mothers resident in district (n)*	*Known to register*		*Not known to register*	
			n	*%*	*n*	*SCR*
1	146	121	50	34	71	1
2	180	152	69	38	83	3
3	145	127	34	27	93	1
4	183	152	56	31	96	0
5	123	107	58	47	49	4
6	43	35	17	40	18	0
Total	820	694	284	35	410	9

SCR, Satisfied criteria for register.

Table 2 Children born between 1984 and 1989 identified from the register and information available on child health list

District of residence at birth	*Total (n)*	*Number still alive and living in district*	*On child health systems*	
			n	*%*
1	85	66	50	75.8
2	186	134	69	51.5
3	65	46	34	73.9
4	104	88	56	63.6
5	86	73	58	79.5
6	54	39	17	43.6
Total	580	446	284	63.7

information systems, the estimated rate was 6.0/1000 live births. Of the 162 children on the register who could not be identified from the child health system as having one of the disabilities sought, 98 had cerebral palsy, 24 had sensorineural deafness, and 40 had severe vision loss.

There was some variation between districts in the degree of mismatch between the information from the local child health systems and the register (tables 1 and 2).

Discussion

Child health computer systems contain some information about virtually every child born in England and Wales. In part, the success of the immunisation programmes has been the result of the completeness and accuracy of demographic information on these systems.[11] In addition, however, considerable time and effort is also spent on the health surveillance of preschool children. This process generates large amounts of information that is entered into child health systems. The focus of this surveillance is to identify the health and educational needs of individual children.[12] Because of this, the information is coded in a way that guides service provision and decision making about individual children. For example, the child is often described system by system as satisfactory (S), problem (P), observation (O), treatment underway (T), referred (R), etc. Outside this context, the information is uninterpretable unless there is additional coding on the type of condition present, or the impairment or disability arising. Even when this information is present, as on the special needs module, there is a wide variation in the way the severity of disability is described, and information on the child's health and abilities might not be updated. Thus, it is not surprising to find that it is not possible to use these data at either local or national level either to provide information on the health needs of the population as a whole or to examine the prevalence of disorders in relation to birth weight, geographical area, pattern of care, or time. Our study confirmed that this unsatisfactory situation continues.

One unifying feature in many systems is the use of diagnostic codes, either ICD-9 or ICD-10, and more recently Read codes. We decided, therefore, to use diagnostic codes to ascertain whether children with particular conditions could be identified from child health systems, and to use a well established register for comparison.

There were two types of mismatch. First, there were false positives. These were children who had a diagnostic code on the child health system which suggested that one of the three conditions sought was present, but who did not meet the criteria inclusion on the register. The high number of false positives could be a result of a failure to update the records of children who are thought to have one of the conditions at a younger age but who turn out not to have. They include children who have a vision or hearing problem that is less severe than the threshold for inclusion on the register, and mismatches in the perception of which children should be included under the umbrella term of cerebral palsy. Although we have regarded the register as a "gold standard" in this comparison, there may, of course, be interobserver differences and reporting inconsistencies in the register. We try to minimise these by using a standard format for describing the children,[13] but differences in definition and in the ways of describing impairment and disability in children, and variations in the availability of diagnostic services, might also contribute to unreliability of data.

Second, there were false negatives, children who did not have one of the selected codes on the child health system but who were on the register. These could arise from failure to update records after a diagnosis is made or the use of ICD codes to describe a child that are different from those selected for use in our study. Children who are identified on the population register but have moved out of the area might no longer be identifiable on the child health system. This is because the child health records move with the child. Therefore, using child health information systems to study birth cohorts is difficult. In our study, we excluded children known to have moved out of the area from the register list, so population movement was not a major contributor to the mismatch. In addition, we excluded children on the population register who had died.

We concluded that potentially child health systems can provide valuable health information on all the childhood population. Therefore, it was disappointing to find that it is not yet possible to compile accurate prevalence information on conditions leading to motor and sensory disability in young children. Indeed, it does seem that, in general, the information within child health systems is not easily accessed either for assessing population needs, as a basis for audit, or as a framework for population based research. The key problems seem to be a lack of agreement about the ways of describing children, wide variations in the computerised systems used, and the unsatisfactory nature of the organisational interface between those who regularly examine babies and children and those who are responsible for the information systems.

Professional and government bodies are now pressing for a more rational systematic approach to recording, collecting, and collating information on the health of children in the community.[1 3 14] To achieve this, a number of steps will need to be taken. Data items must be agreed and specified clearly, and systems will need to be accredited in terms of their ability to capture the data specified. The systems will need to be designed in a way that makes data accessible for analytical as well as operational purposes, taking into account the differences in the population base required for these two purposes. In time, a national database derived from local systems could then be developed. These steps can be taken, however, only if it is agreed at all levels of the health service that this is desirable and if appropriate funds are made available to address the current problems.

Until then the answer must be "no" to the question posed in the title—"Can routine systems be used to monitor serious disability?". For the time being, separately funded studies and population registers are needed to answer simple questions on the prevalence of disabling conditions in childhood.

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